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The Rise and Fall of the Patient Forum

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This paper is circulated for discussion purposes only and its contents should be considered preliminary.

Summary

The circular, ‘A Stronger Local Voice’ (Department of Health 2006) published in July announced that Patient Forums in England will be abolished to be replaced by local authority run Local Involvement Networks (LINKs). What went wrong with Forums? What was wrong with Community Health Councils before them? Will LINKs be more successful than either of them? Is there anything to be gained from another major reorganisation of public involvement arrangements?

Introduction

For the last two and a half years I have served on a Primary Care Trust (PCT) Patient and Public Involvement (PPI) Forum in the North of England (not in the city where I work). The PCT, which is coterminous with a unitary local authority will continue in its current form despite the recent reconfiguration of PCTs, however the PPI Forum will be abolished in July 2007 to be replaced by a new type of public involvement body to be known as a Local Involvement Network (LINK), which in the new arrangements will be convened by the Local Council’s Overview and Scrutiny Committee, (OSC).

The members of the Forum of which I am a member are drawn from a range of backgrounds. For many of us the first year was unrewarding as we struggled to find a role and became increasingly frustrated in our dealings with the PCT. It was only after about 18 months when some members became closely engaged in monitoring the performance of the out of hours GP service and the town’s new Walk-In Centre, that we finally began to feel we were adding any value. Given the fact that it took this length of time to get going, it is disappointing that the Forum is now to be abolished.

Replacing Community Health Councils (CHCs)

The imminent reorganisation of public involvement follows only three years after the last reorganisation, when the CHCs were replaced. Their abolition, described as one of the most controversial changes announced in the NHS Plan (Coulter 2005) followed several years of decline. Established in 1974, it could be argued that CHCs lost their focus in the 1990s with the creation of the internal market. They became just one of many voices representing the public and to some appeared, “parochial, quirky and irrelevant” (Pickard 1997). Nevertheless, to replace them in 2003, the Government was forced to set-up by six new bodies, (see figure 1).

Figure 1

Six new bodies set up to replace CHCs in 2003

Overview and Scrutiny Committees (OSCs) – part of local government arrangements and focussed on monitoring service provision

Independent Complaints Advocacy Service (ICAS) – voluntary sector organisations supporting patient complaints

Patients Advice and Liaison Service (PALS) – linked to PCTs and Trusts providing patient advice and support

Commission for Patient and Public Involvement in Health (CPPIH) – soon to be abolished arms length body managing ICAS and developing patient and public involvement arrangements

Patient and Public Involvement Forums – representing service users and local residents

Forum Support Organisations (FSOs) – voluntary sector organisations offering administrative support to Forums

The new system cost considerably more than the old. According to Government figures it cost £18 million to set-up CPPIH and to lay off CHC staff during 2003-2004. Since then, the running costs of the FSOs and CPPIH have been £10 million per annum more than the cost of running the CHCs (Department of Health 2005a).

Many of the people and organisations involved in the new bodies lacked experience and the system seemed to be needlessly complicated. Despite the extra cost, doubts emerged about whether the new system could be any more effective than the CHCs (Baggot 2005) and it was not long before the risk of fragmentation, overlap and muddle started to manifest itself (Coulter 2005).

Perhaps because of concerns about the cost of scrapping the CHCs and setting up CPPH, Forums were set up in performance management induced frenzy. After a period of great uncertainty and several stays of execution, CHCs were formally wound-up at the end of 2003. As a result the Commission for Patient and Public Involvement in Health (CPPIH), was given the task of setting itself up and recruiting over 5,000 people to sit on PPI Forums before the end of the calendar year. I was recruited on the back of a 10 minute telephone conversation. I was required to attend two training sessions, which were led by several CPPIH staff some of them on short term contracts who seemed to know much less about the health service than most of the new Forum members. With the clock ticking down, the Forum had to hold its first meeting before the end of December 2003 and the first public meeting by the end of January 2004.

The pressure the Department of Health placed on CIPPH to get the Forums up and running in such a tight time frame almost certainly led to a series of problems that contributed to the perceived failure of the Commission and to poor working arrangements in many of the newly created forums. Appointments were rushed, training was inadequate and guidance on important issues for Forum members such as travel costs, conflicts of interest and Police checks seemed to evolve rather than having been thought through in advance.

Being a Patient Forum Member

So what was it like being a Forum member and what did we do? As an ex Health Service Manager, I found it rather depressing to be 'involved' and be 'consulted'. Without the status of an NHS badge, a suit or a uniform, one's opinion suddenly appeared to become of less value, even if it is offered in the official capacity of a Forum member. Members were often 'consulted' by managers coming to a meeting with a set of Department of Health pre-prepared slides. We were occasionally asked for our views; sometimes our views were even recorded. Our letters and reports were sometimes responded to without prompting, but I am not sure that we can honestly say that we had or were expected to make a significant impact on healthcare in the locality.

It seemed that most Department of Health officials and NHS Managers made an assumption that forum members were retired, had nothing better to do than attend day time meetings and that they are happy to sit passively and only talk when they were spoken to. Even in meetings with managers and healthcare professions when Forum members were invited, many managers and health professionals would continue to talk in 'NHS manager speak'. To such an extent that as the ex NHS manager, I often found myself in an interpreter type role, especially in the first year or two of the Forum.

The CIPPH contracted a range of voluntary associations to provide the role of Forum Support Organisation (FSO). Some FSOs were better prepared than others, but all faced the same problem of timescales. Our FSO appointed a new member of staff to support two Forums. The normal time lags associated with recruitment meant that she was not in post until after the first two meetings had taken place. Like all Forum members she too faced a steep learning curve and often was not much clearer than Forum members about what was expected of the Forum during our first year.

As an example of poor practice, in January 2004 the Department of Health contacted all Forums and asked them to offer comments on the details of the new GMS contract. My colleagues and I were all copied the long consultation document. Faced with this long and complicated circular, two of our members were never seen again. A conservative estimate suggests 11 percent of Forum members

dropped out in the first year (Baggot 2005). In our area, this figure was more like 30 percent. This type of inappropriate use of Forums occurred time and time again in the first 18 months as managers and civil servants struggled to work out who should do what in the new system. In our first year we were also asked to comment on closures of and changes of location for Pharmacies, without any understanding of the regulations (a role apparently inherited from CHCs). We were asked to comment on the relocation of the Podiatry services (arguably an OCS role) and a Community Midwife came to talk to us with no clear understanding of what we did or why she was talking to us.

The relationships with the local PCT took a long time to develop. The PCT Chief Executive came to the first two meetings and made some positive statements about involving us and how important our role was, unfortunately all the other demands on his time meant that we did not see him again for nearly two years. Not all his staff were quite so attuned to the importance of involvement. In March 2004, the PCT produced a Patient Carer and Public Involvement Strategy. We found it ironic that there were constant references to working in partnership with the Forum, however, because the document had been thrown together just in time for an end of March deadline, we were not involved in the production of the document. Section 11 of the Health and Social Care Act, placed a duty on Trusts, PCTs and SHAs to involve and consult with us (Department of Health 2001) but it in the early days of the Forum, it appeared that the PCT could say they were involving the Forum, without actually having to enter into any meaningful dialogue with us.

The introduction of the Annual Health Check system in April 2005 created a new dynamic in the relationship with the PCT; it gave the Forum the opportunity to report the PCT to the Healthcare Commission if it felt the PCT was not fulfilling its duty to involve us. When the PCT sent us 36 pages of tabulated information making up the first Health Check submission, we found buried deep in the document, a measure of Patient and Public Involvement. The PCT had given itself a green light against this measure without consulting us. The Forum commented to the Healthcare Commission that we would have much preferred a 'could do better' rating.

Throughout the first two and a half years, it has been the Director of Public Health, who has been the star turn for the PCT. She has turned out to many evening meetings and briefed us on a range of public health issues. She has not talked down to us, has been informative and enthusiastic and has been very patient even when members have asked her the most banal questions.

Working relationships have improved significantly of late and with two and a half years experience, the FSO knows exactly what it is doing, many of the members have developed areas of interest and

expertise and PCT managers seem to have an interest in increasing the range and degree of involvement in service planning and development.

Writing on the wall

However, this would not be the NHS unless a reorganisation came along every few years to fracture established working relationships. The writing has been on the wall for Patient Forums since spring 2005, when 'Creating a Patient Led NHS' (Department of Health 2005b) suggested the existing mechanism for public and patient involvement would need 'to evolve'.

In February 2006 the Department of Health set up an 'Expert Panel' to review patient and public involvement. The Panel did not appear to include anyone who had any day-to-day experience of working with Forums, and contained no Forum members. Therefore it was no surprise that PPI Forums were written out of the new system of PPI. In July 2006, the Department of Health published '*A Stronger Local Voice*' and '*Health Reform in England: update and commissioning framework*', which contain the details of the new patient and public involvement arrangements. Although '*A Stronger Local Voice*' calls itself a consultation document, the abolition of Forums appears to be non-negotiable.

Forums are dead, long live LINKs

It could be argued that the reconfiguration of PCTs and Ambulance Trusts and the creation of Foundation Trusts are as much to do with the downfall of the Forums, as is their apparent failure to deliver an improvement in PPI. Nevertheless the new arrangements proposed in '*A Stronger Local Voice*' are much more radical than merging a few Forums to absorb Acute Trust Forums into PCT Forums and matching the Forums to new PCT boundaries. The CPPIH has already been told it is to be abolished; the Forums have now been told they will go to within a year. The whole structure will be handed over to strengthened Local Authority OSCs with new LINKs feeding into them rather than directly to NHS organisations.

LINKs will share boundaries with Social Services Departments of local councils; as a result somewhat ironically, many LINKs will have boundaries very similar to the old CHCs. Membership and management arrangements have been left to individual Local Authorities to determine. Again there is some irony here as one of the criticisms of the CHCs in years gone by was the political agenda of the Local Authority appointed members. The power to inspect premises has been moved from Forums to the OSC along with the budget for Patient and Public Involvement; meaning that Local Authorities rather than the NHS or Central Government will have the problem of insufficient funds to do the job properly.

'A Stronger Local Voice' suggests current Forum members might wish to get involved, but it offers no suggestion that the OSC will be obliged to take them; instead the circular is quite clear that OSCs will need to make their own arrangements to attract and retain appropriate membership. The CPPIH has concerns that the new arrangements will simply replicate past mistakes. In a press release in July 2006, the Chair of CPPIH appeals to the DoH not to ignore the contribution of 5,000 Forum members. It suggests that LINKs must be independent, properly resourced and that there must be no repeat of the vacuum that followed the abolition of the CHCs. Even if the resources are adequate and even if the OSCs are able to set up LINKs before the Forums go, it is inevitable that there will be another period of at least a year of uncertainty and confusion as the new arrangements bed down and managers, volunteers and local government Officers get used to the new arrangements. The vacuum and the confusion appear inevitable, as does inconsistency of approach. Again, this was a criticism levelled at CHCs.

Conclusion

There was a need to review and update PPI arrangements in England, mainly because involvement arrangements have not kept up with the formation of Foundation Trusts and PCT reconfiguration. However some of the rhetoric in *'A Stronger Local Voice'* about empowering citizens to give them more confidence and more opportunities to influence public service, sounds rather hollow to those of us who have tried to be 'involved' for the last few years, simply because whatever the system, the culture is not yet in place to treat members of the public as partners in the planning and management of services.

PPI happens when patients, carers and members of the public give up their time to involved. In 2003 the abolition of CHCs created a group of unhappy ex CHC members, only a few of whom went on to join a PPI Forum. They had given up large amounts of time some of them over many years and were hurt to be rejected. I suspect there may soon be a group of ex Forum members who will also feel rejected by these new arrangements. Unlike Managers caught up in reorganisations, volunteers can and will simply walk away if they are not happy and feel they are not getting any satisfaction from their role.

It is difficult not to be cynical about the future. Replacing PPI Forums does not seem to be the answer to improving patient and public involvement. Another reorganisation, will simply lead to confusion, uncertainty and another year or two of time spent in setting up and getting used to the new arrangements. The fact that the new arrangements have echoes of the old CHC set-up is just a further reason for cynicism. The current top down performance management approach to running

the NHS in England, simply does not allow opportunities for patient and public involvement in the planning of NHS services.

Key points:

- Arrangements to replace Community Health Councils in 2003 were over complicated and their introduction was rushed in response to political pressure.
- The Government is now planning to introduce a new system of patient and public involvement in Health in England in 2007
- Patient and Public Involvement Forums will be abolished. The knowledge and experience of current PPI members is likely to be wasted
- Local Government Overview and Scrutiny Committees will be at the centre of the new arrangements, supported by Local Involvement Networks
- The new system has echoes of the old Community Health Councils.
- It remains doubtful whether changing the structure of Patient and Public involvement will to lead to a significant improvement in the degree to which members of the public can influence health policy and planning

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